

██████████ STORY.

██████████ was born on 13th of June 2008 by emergency caesarean at 37 weeks. Right from the start she had trouble sucking and stopped breast feeding at 3 months of age. She continued to struggle sucking from a bottle and had to go onto pureed foods at 5 months of age. She always rattled in the chest when breathing and blowing bubbles so we took her back to the hospital 3 times. Each time they told us she had bronchiolitis. ██████████ was behind in her milestones yet when we questioned this we were told it was because of the bronchiolitis and when she grew out of it she would catch up. At 12 months of age she fell ill and we took her back to the hospital where once again they listened to her chest and said the same thing again bronchiolitis, after a lot of arguing they agreed to do a chest x-ray and found out her left lung wasn't working because she had pneumonia and had contracted influenza A. She was admitted and while in hospital 3 days later contracted swine flu. Five days later we were sent home and put on a waiting list to see a paediatrician. Approximately 4 weeks later for no apparent reason she started vomiting and stopped breathing. After we got her breathing we rushed her to our GP and he said he thought she had a seizure and did an urgent referral to the mater hospital. After extensive testing we were given an interim diagnosis of cerebral palsy but they did not know what was wrong with her but she was able to roll over sit up in a high chair, feed herself, reach out and pulls herself up and was starting to talk.

It was not long after this that her seizures started to increase to the point where she was having hundreds of tonic clonic seizures each day. Her seizures would cluster and range from ten to sixty plus in the space of half an hour to one hour all day and night. During this time she started to regress to the point she could no longer do anything she could not eat. roll over lift her arms or legs stopped talking everything went to the stage she was the equivalent to a new born child. She had to have a fundoplication to stop her reflux and aspiration; she had a gastrostomy because she could no longer eat. In 2011 after she had started being peg fed it was decided to try her on the ketogenic diet as her seizures were still out of control despite all the meds she was on or had tried. The diet worked to the extent her seizures were reduced but always with meds which was proving to be difficult as they would stop working and new ones having to be introduced and we were using midazolam regularly as her rescue medication.

Around June 2013 her seizures increased and we had to take her emergency to find out what was happening and maybe increase her medication. While in ED she had a seizure which lasted about 3mins and they gave her midaz. and the seizure stopped but one of the ED doctors said she was in status because her heart rate was elevated we told him we the seizure had finished but he did not listen and gave her more midaz which caused her heart rate to increase even more. It ended up they gave her 3 doses of midaz, 1 dose of clonazepam and fenobarbitone. The doctor then said to us the fenobarbitone can cause breathing difficulties and we were two steps away from deciding how much effort we would put into keeping her alive and we told the doctor we expected everything possible to be done. She settled down and was sleeping so I had to go home for our other kids while my wife stayed at the hospital. I returned about half an hour later to find my daughter not there and they told me she was in resuscitation. ██████████ had stopped breathing and they were resuscitating her. After they got her breathing again they told me that because of the side effects of the drugs they had given her. Her body had filled up with carbon dioxide, she had stopped breathing and the ketogenic formulae she was having at the time had gone into her lungs. She spent seven days in icu and did not wake up for four days. Once she woke up her seizures were uncontrollable and it was decided to take her off the

diet to put her on steroids to try and control her seizures and in the meantime they would try her on ospolot and after three weeks she was discharged and we were sent home. Three days later we were back in the hospital as her seizures were uncontrollable and saliva was bubbling out of her mouth and nose. We spent another three weeks in hospital during which time her poo had black. They performed an endoscopy which showed she had bleeding stomach ulcers from the meds and bleeding below the esophagus from reflux. By this time she was on five different meds and it was decided to put her back on the ketogenic diet to try and get her off some of the meds as the ulcers now ruled out steroids and a whole range of medications and she ended up on the keto diet and tegretol. ■■■ had been having regular MRIs to monitor her brain because of reduction in white matter, During these regular procedures something which they thought was a tumor most probably a glioma. It was decided to monitor with a MRI every six months as the risks of a biopsy outweighed the benefits and in 2014 it stopped growing and they changed it to a lesion and regular MRIs done every twelve months.

February 2015 ■■■ developed stomach problems and her poo turned black again and we were waiting for an appointment to see a gastro specialist. During this time her seizures increased again and it was decided with her neuro team to wean her off tegretol as her stomach ulcers had flared up again. We started weaning her the end of april and got halfway through the wean when it became apparent the wean was not working so I rang the hospital and asked them what the plan was because her seizures were uncontrolled and continuous, The hospital said there is no plan as there are no meds left to try. It was at this stage we decided to try cannabis oil. She had her first dose on 15th may 2015 and after one week her seizures stopped and was weaned off the tegretol and for the first time in six years was on no epilepsy meds. The effect was nothing short of amazing she was alert, happy going to school 5 days a week even swimming at school and for the first time in her life progressing rather than regressing. She has been on no epilepsy medications for over a year. In January she had her regular MRI and we received a phone call from Geoff Wallace her neuro and head of neurology at LCCH to tell us in his words the lesion on her brain is gone it has just disappeared.

Since the 15th may last year when she started on the cannabis oil she has been on no epilepsy medications, has not been in hospital for epilepsy where she used to spend three or more months a year, the lesion on her brain has gone and she has improved in every aspect of her life. The medical profession has told us they do not know what is wrong with our daughter. They think she has an unknown regressive syndrome and there is no cure for what she has. They gave an interim diagnosis of cerebral palsy so we would get the support we need and on her seizure plan her diagnosis is UNDETERMINED COMPLEX NEUROLOGICAL DISORDER AND REFRACTORY EPILEPSY. Our daughters time with us is very limited and the cannabis oil is not a cure but what it gives her is quality of life and without quality there is no life and the medical profession cannot give this to her with medication as they have caused her severe side effects and failed to control her epilepsy.

Three weeks ago ■■■ caught adenovirus which affected her respiratory system and her stomach and as she got sicker her seizures started again to the extent the oil was not working. We called an ambulance and she went to emergency where her seizures increased and none of the rescue meds were working. They gave her Kepra iv with no result so they tried Fenotone iv, her seizures increased and she stopped breathing five time as a result of the meds. There was nothing left to try and she went to icu and was put on hourly doses of diazepam which reduced the seizures a bit and she was sent to a special epilepsy ward but her seizures continued where she was sedated to try and stop the seizures. We were given the option of staying at the

hospital or going home and because of not being able to give her a stronger oil which had been provided to us we went home. Since starting her on the stronger oil the seizures have all stopped but the virus has turned bacterial and she is still ill but now we are faced with the dilemma of what to do.

Two weeks ago on Saturday morning she became very ill and her seizures increased so we took her to the hospital and in the emergency dept. she had some seizures and was given multiple rescue medications which caused her seizures to increase and she was at risk of respiratory failure and was moved to icu. During this time her chest was x-rayed where it was discovered she had a severe pneumonia either a hospital acquired pneumonia or bacterial pneumonia caused by aspiration as a result of the side effects of clobazam which affects her ability to swallow and that she had been put on two weeks earlier. During the afternoon and night her seizures increased to the stage where she was having a seizure approximately every five minutes. They tried keppra, diazepam, fenobarbatone, fenotone, epilum, paraldehyde, clonozapam and clobazam but the seizures continued. Early Sunday morning I decided that despite the threats from the hospital of calling the police during the previous visit I would try the cannabis oil she had been using. While waiting for the oil to be brought to me I received a call from icu at 6.24 am that my daughter had gone into respiratory arrest and was being resuscitated and I would have to wait before I could come up. It was just after 9am when I could go up, she was connected to a respirator, an eeg, had been given propofol to sedate her and a heavy dose of midazolam but the seizures continued unabated. I gave her 5ml of oil and waited. Half an hour later her seizures spread to 15 mins apart then half an hour apart. I gave her another dose and the seizures stretched even further apart and after the third dose they were gone. My wife and I were at the stage where we had to discuss what we would do if her seizures did not stop but fortunately it did not come to that.

Since starting [REDACTED] on the cannabis oil we have told the hospital about it, they spoke to DOCs about it who said put it on her file regarding the oil. We have completed the pathways to medical cannabis at the hospital and they have documented it as doing her no harm and all her medical team have seen the benefits first hand. There is nothing left for our daughter without the Cannabis Oil and we will not standby and watch her slowly waste away.

- What concerns us is if the product which gets approved does not work for our daughter (like all other Anti Epileptic Drugs she's been on) or if it is unaffordable what do we do? When what we are using, the Whole Plant Cannabis Oil, works.
- The bill being considered puts restrictions to stop the misuse of Cannabis Oil, however, I do not understand how Cannabis Oil can be misused. The same restrictions don't apply to midazolam, diazepam or morphine which are easily obtained with a prescription and can be misused quite easily. These AEDs are returned to the pharmacy once expired but there is no accountability.
- As a parent of child suffering refractory epilepsy, I see this bill as taking everything or what's left of the little bit of hope that the "Whole Plant Cannabis Oil" has given our daughter. Let's be specific here. I am talking about Whole Plant Cannabis Oil. Not recreational or otherwise.
- Based on [REDACTED] experiences and hearing from other parents of kids like [REDACTED], no one medication works for all and some work for a period of time and then cease. What hope is there for kids with refractory epilepsy?
- There is a need for patients using the Medical Cannabis Oil to be assessed on case by case basis as per my point above.

The power is in your hands so please do what is right and let us give [REDACTED] what she needs. [REDACTED] deserves to live her life with dignity and at least some quality. After all, [REDACTED] is surviving on her own strength. She is not on life support or need anything to keep her alive. Her only fight is against seizures and no one and no body has the right to take that away from her.

Thank you,

[REDACTED]